

End the ignorance, injustice and neglect of people with M.E.



Action for M.E.'s
2016 – 2021 strategy

Pictured on the cover is
Shass Blake, who has M.E.

Shass lives in Bristol and was
diagnosed with M.E. in her
mid-thirties after decades
of symptoms.



Meeting need now, securing change for the future

Over the past 30 years, Action for M.E. has worked to improve the lives of people with M.E., taking action to reduce the isolation experienced by many and working to create change.

Despite our best efforts, children, families and adults affected by M.E. still face ignorance, injustice and neglect. This five-year strategy seeks to tackle this with even more ambition, more investment and more creativity.

Based on the views and experiences of more than 500 children, young people, parents and professionals, we have now updated this strategy to include our promises to children and young people living with M.E.

We are a small organisation that regularly punches above its weight. We are leading, with others, a growing community of supporters working to create real change on the scale so urgently needed at a local, national and international level.

There is much to do and we cannot do it alone. We will seek to work with others where possible to avoid unnecessary duplication and to create a stronger voice for the 250,000 people in the UK with M.E., and the many more children and families directly affected by it now and in the future.

We invite you to join us. Together we can stop M.E. stealing lives.



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Jonah Grunsell
Chair of Board of Trustees



Sonya Chowdhury
Chief Executive

1 in 250

people in the UK have M.E., including 1 in 100 young people aged 11-16 years.

Suicide is **6 times** more likely in people with M.E. and CFS compared to the general population.

M.E. is the **most common** cause of long-term absence among school children.

More than 80%

of people with M.E. are primarily cared for by a family member, but almost none receive a care assessment.

Less than 1 in 10

people with M.E. are in full-time paid work, education or training.

25%

of people with M.E. are severely affected, house or bedbound and unable to care for themselves.

M.E. is in the **top three** most challenging illnesses for GPs and has been for more than 10 years.

Research indicates that M.E. indirectly costs the UK **£102 million per year** as a result of lost employment and productivity.

97%

of people with M.E. may be eligible for social care, yet only **16%** have had a social care assessment. Of these, only **6%** had been awarded a care package.

Sources: National Health Service, Chronic Fatigue Syndrome (2009); Crawley et al, Unidentified CFS/M.E. is a cause of school absence: surveillance outcomes from school-based clinics. BMJ Open (2011); Dowsett and Colby, Long Term Sickness Absence due to ME/CFS in UK Schools: An Epidemiological Study with Medical and Educational Implications (1997); Action for M.E., M.E. time to deliver (2014); Collin S et al, The impact of CFS/ME on employment and productivity in the UK: a cross-sectional study based on CFS/ME National Outcomes Database (2011); Chang et al, Mortality of people with CFS. Lancet (2016); Aviva, Health of the Nation report (2013); Action for M.E., Close to collapse (2016)

“I cannot sit, stand or walk without feeling pain”

Richard worked in IT when he became ill with M.E. He told us:

“I’ve always been a hard worker and put in lots of overtime to help pay bills. But I was fired from my job because of the amount of time I had off ill. The loss of earnings had a huge impact on me and I suffered a lot from worrying about keeping a roof over our heads.

“I cannot sit, stand or walk without feeling pain. The only time it subsides is lying down, although even then the aching in my legs often prevents me from sleeping. Reading a book or watching television is impossible because I cannot concentrate and my head and eyes hurt.

“I contacted Action for M.E. and was blown away by the help and support I was given. If it wasn’t for Action for M.E., I would never have got through the process of claiming benefits. I cannot emphasise enough how valuable this was.”



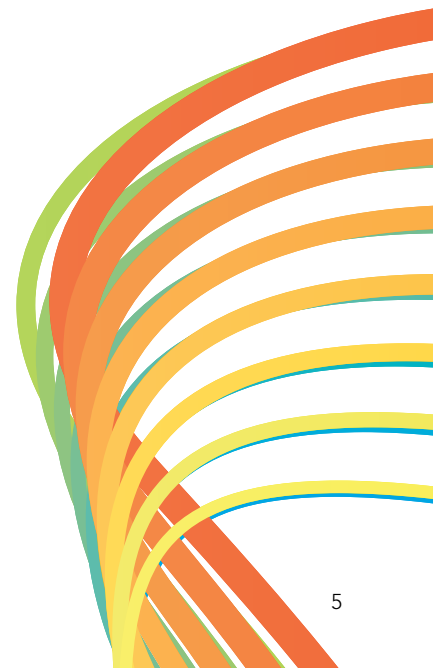
What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. It affects around 35 million people worldwide.

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body and brain’s inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms.

We recognise that it is quite possible that M.E. may be an umbrella term for a number of illnesses. Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or CFS/M.E. is often given. Action for M.E. uses the terms M.E., CFS and M.E./CFS because we do not wish to withhold support from those who have been given a diagnosis of CFS, as opposed to M.E.

For the majority of children, young people and adults with M.E., supported illness management advice is the most they receive. We have not seen the investment in support and care, in research and ultimately in treatments that is needed. It is time to take a stronger, united, collaborative approach to creating that change.



Our vision is a world without M.E.

Our mission is empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

Action for M.E. was established in 1987, when our founder Sue Finlay received 15,000 letters in response to her *Observer* article about the difficulties of living with M.E. Few doctors recognised the illness, and the need for services and support was desperate.

The past three decades have seen us build on the connections Sue made to reach more people affected by M.E.

Recognising that we could achieve more for children, young people and families affected by M.E. by coming together, Action for M.E. merged with children's charity, Association of Young People with M.E., and launched our new children's service in April 2017.

Now we employ 20 part-time and full-time staff, supported by around 70 volunteers in our Keynsham and Scotland offices and at home.

Those who access our services tell us that they feel less isolated and part of a community, and we are starting to see increased recognition of the impact of M.E. among the press, the public, professionals and policy-makers.

However, there is still a long way to go.

At our *Living and learning with M.E.* event in Edinburgh in March 2016, Belle & Sebastian singer songwriter Stuart Murdoch spoke about his experience of M.E.

"Sometimes I feel like I'm part of a secret society," he said, referring to the isolation that comes with M.E. "What I really want is just to be part of society."

What will it really take for everyone affected by M.E. to feel that they belong?



Over the next five years, our purpose is to end the ignorance, injustice and neglect experienced by people with M.E.

We will do this by meeting need now to improve the lives of children, young people, families and adults affected by M.E. while taking action to secure change for the future.

People with M.E. are at the heart of everything we do. We asked and we listened, and have identified a number of challenges that continue to exist for people affected by M.E.

Everything we do over the next five years will be in service of achieving three goals, which we call our strategic touchstones, to tackle these challenges.



By collaborating with those who share our vision and purpose, we can make the most of the resources available to us.

Around 50% of our activities will directly focus on targeting information, improving support and reducing isolation to **IMPROVE** the lives of people with M.E. To be as effective as possible, 30% of our activities will focus on facilitating more action, more influence and better understanding of M.E. to **INSPIRE** action at all levels; and 20% of our activities will be focused on bringing more research, more money and more people into the field to **INVEST** in change.

Everything we do will work towards meeting one or more of our objectives. We will only consider undertaking an activity if it improves the lives of people with M.E., inspires action at all levels, or supports investment in change.

We will improve the lives of people with M.E.

"Before I got ill I danced my whole life, and went to drama group. Overnight I had to stop acting and dancing, because they require so much energy that I don't have. My friends didn't want to know me when I got too ill to be able to go out shopping and to the cinema with them. Now I lie down 95% of the day and have most of my appointments from home. I also have to use a wheelchair all around the house, as I can only walk about five steps. Every day I get a little more ill."

Olivia, 21



The challenge

Despite the excellent work of charities and organisations such as Action for M.E., people with M.E., their families and professionals tell us that there is still a lack of access to good-quality information at the time it's needed most. Alongside this, more direct support to access local services is needed as well as practical support with daily living tasks.

Children, young people and adults affected by M.E. have also asked us to provide advice and resources to better manage the illness and its impact based on the experiences of others with M.E. Some local support groups have told us they would like us to work with them more directly to increase the number of people they can reach and enhance the support they offer.

Our objectives are to:

- provide targeted information
- provide improved support
- reduce isolation.

The impact of our work so far

In early 2016 we surveyed our Supporting Members. Results showed that:

- 91% feel better informed as a result of being a member of Action for M.E.
- 76% feel a stronger sense of hope knowing that we are working with others to tackle important issues for people with M.E.

One supporter told us: "Action for M.E. is such an important and very necessary support system for newly diagnosed people and their carers."

Another said: "It is comforting to know you are always there to turn to in times of particular need or difficulty."

Our promises: how we will build on the difference we've already made

We will provide an information support service that supports children, young people and adults affected by M.E. to make informed decisions about living with the impact of the illness.

- We are extending our telephone and email information service to reach 20% more people from 2016 to 2021, including piloting an online service where people can book a session with an Information and Support Officer.
- We are increasing the reach of our Online M.E. Centre by 20% from 2016 to 2021, empowering more people affected by M.E. to make informed decisions about living with the impact of the condition.
- We are continuing to provide printed information for those people with M.E. whose symptoms prevent them from accessing resources online.
- Informed by children and young people, we will develop targeted resources to ensure that they and their families have the information and support they need for living with M.E.

We will reduce the isolation experienced by children, young people and adults with M.E.

- We will offer children and young people with M.E. the opportunity to connect with others affected by the illness, using methods including online platforms and face-to-face meetings to facilitate friendship, support each other and share experiences.
- We will ensure that children and young people who are too ill to communicate online can choose to receive letters and cards from other children and young people living with M.E.
- We will continue to offer online forums for young people, parents and carers, and adults with M.E., enabling them to share information, peer-support and friendship, and feel less isolated.

We will increase practical support for people with M.E. by linking them with local volunteers.

- We are exploring the development of an innovative project to transform how people with M.E. can identify and connect with local volunteers to support them with routine daily tasks.

We will increase access to advocacy to enable people to secure appropriate services, support and care.

- We will develop our specialist welfare advice service to reach 20% more people over five years and ensure that they are able to access the financial support available to them.
- We will secure funding to pilot an advocacy service to support people in accessing the services and care they need and seek to roll this out nationally.
- We will provide specialist support and advocacy for children, young people and families, including face-to-face where required in complex cases, who face barriers in accessing the support they are entitled to.
- We will support and promote the use of technology to reduce isolation and enable children and young people to access appropriate education through a mobile robot avatar.

We will increase information to people with M.E. to enable them to better manage the illness, its symptoms and its impact.

- We will fundraise to pilot a one-year programme of self-management webinars for 200 people affected by M.E., based on the experience of people with M.E. and professionals.

We will improve collaboration with local support groups to achieve their aims and objectives.

- We will undertake a consultation with local M.E. support groups to inform our activity.
- We will develop a model of support with, and for, local M.E. support groups to be offered to them to enhance their reach and reduce isolation.

We will inspire action at all levels

Action for M.E.'s 2015 Close to collapse survey found that 65% of people with M.E. who responded could not independently and reliably access primary healthcare settings such as their GP surgery, dentist or optician, and half agreed that they felt judged negatively because of their M.E. diagnosis. Only 16% of respondents had received social care assessments, with misunderstanding, misinformation and stigma surrounding the label of M.E. acting as a deterrent to asking for help for more than a third.



The challenge

The opportunities to input into policy work are wide but the potential to create real change is limited. We therefore have to ensure a very clear focus for our policy work and to take action at all levels: local, national (UK-wide) and international.

The move towards devolved decision-making and budgetary control at a local and national level creates opportunities as well as challenges and we must ensure we identify and respond to these. During the course of this five-year strategy, we will begin to see the full impact of the Brexit referendum result and face a general election.

Our objectives are to inspire:

- better understanding of M.E.
- more influence
- more action.

The impact of our work so far

In July 2015 we sponsored *Webinars for GPs* to run a pilot webinar on M.E., led by Dr Hazel O'Dowd, Clinical Champion for CFS/M.E. Services for Avon, Gloucester, Wiltshire and Somerset. This attracted more than 150 GPs and had its running time extended by an hour to accommodate the many questions they asked.

All those who shared feedback rated the webinar as good, very good or excellent. As a result of the training they received, GPs said they would be:

- more aware of M.E. and how to support patients better
- more proactive in management of symptoms
- more comprehensive when carrying out examinations and tests
- more confident in diagnosis and referral.

Our promises: how we will build on the difference we've already made

We will develop a focused programme of UK policy work.

- We are working more effectively across the UK's four nations, developing a nation-specific programme of activity.
- Through our programme of nation-specific activity, we are taking a more targeted focus on issues specifically related to health, employment, education, social care and welfare benefits to maximise impact and influence, for example engaging with the National Institute of Health and Care Excellence regarding the review of its guideline for M.E.
- We are building on the success of our innovative employment support pilot, Support, Empower and Employ people with M.E. (SEE M.E.), to improve outcomes for people with M.E. and the professionals working with them.

We will increase the knowledge and understanding of key professionals who work with children and families affected by M.E.

- We will fundraise for a Children's Education Worker to ensure we have the specialist skills and experience needed to best support children, families and professionals to improve children's education experience.
- We will work collaboratively with education, health and social care professionals to ensure they have access to training, resources and high-quality information about M.E. and its impact on children and young people.
- We will continue engaging with parliamentarians and decision-makers to ensure implementation of relevant legislation, enabling children and young people with M.E. to access health services and an education that best meets their individual needs.

We will increase knowledge and understanding of M.E. among primary healthcare professionals.

- We are developing our Online M.E. Centre to share evidence-based information and the experiences of people with M.E., and ensure that this effectively reaches healthcare professionals to improve outcomes for those they support.
- We will recruit a health education specialist for a year to assist us in developing a programme of training and development for primary healthcare professionals so that they have a better understanding of how to meet the needs of people affected by M.E.
- We have sponsored four webinars for 500 GPs and continue to develop this longer-term programme.

We will work at an international level to influence action in the UK to improve the lives of people with M.E.

- We are working with the International Alliance for M.E. to extend its reach and collective influence.
- We are developing an appropriate, well-resourced plan to address M.E. at an international level which will ultimately support our national policy work to secure change for people with M.E. in the UK.

We will work more effectively at a local level.

- We will work with local M.E. support groups to enhance influence and increase understanding at a local level.

We will invest in change

“M.E. has had a very bad press around it in the past, which seems to be slowly changing due to more people raising awareness. It has for such a long time been known as a lazy person’s illness but this couldn’t be farther from the truth. There needs to be so much more done in terms of research and treatment. People with this illness just want to be able to live a normal life again. I would give anything to be in that position.”

Sharon, 40, pictured with her children



The challenge

There is no question that in the past there has not been enough research into M.E., created by a lack of recognition of the illness, a lack of interest from eminent scientists and a lack of funding. Many studies do not include people who have the most severe form of M.E. and we must continue to advocate for a stronger focus on severe M.E. Studies undertaken often feature small numbers and there has been a lack of biomedical focus. However, this is beginning to change with strong collaborations developing such as the UK CFS/M.E. Research Collaborative, of which Action for M.E. is a founding member.

Action for M.E. does not have the large-scale funding required to find a cure for M.E. What we do have is the vision and determination to drive collaborations to stimulate interest and investment which will eventually lead to change.

Our objectives are to:

- invest in research
- raise more money to provide more services
- work with others to create a social movement for change.

The impact of our work so far

News of the M.E./CFS Epidemiology and Genomics Alliance (MEGA) study was met with excitement when we posted it on our Facebook page in May 2016. Rachel posted to say:

“This is just the kind of biological research that M.E. patients desperately need to see happening. It is most encouraging to see that 12 experts across different fields and universities are pooling their expertise to investigate the causes and underlying biology of this disease. The input of researchers with no prior involvement in M.E. will bring fresh eyes to the challenge. It is also great to see that M.E. patients will be actively engaged in developing this study.

“Thank you Action for M.E. for being a part of this and working so hard to make a difference on behalf of all of us.”

Our promises: how we will build on the difference we've already made

We will play a leading role in driving new collaborations to increase interest and investment in research.

- We are continuing to work closely with the UK CFS/M.E. Research Collaborative.
- We will work with people affected by M.E. to ensure their voices, views and experience play a lead role in driving research forward.
- We played a proactive role with the M.E./CFS Epidemiology and Genomics Alliance to secure funding for a big data research study, and continue to actively explore emerging funding opportunities.

We will invest in pilot research projects and bring new researchers to the field.

- We are investing in at least one three-year postdoctoral or PhD studentship at any one time for projects focused on biomedical M.E. research.
- We will support talented researchers to build an independent research career and increase the skills and expertise in the field of biomedical M.E. research through our new Clare Francis Fellowship.

We will invest in the futures of children and young people with M.E. by increasing volunteer opportunities to develop new and existing skills.

- We will train and support children and young people to be peer-supporters and moderators on our forums.
- We will provide support for children and young people to lead and contribute to our children and young people's magazine *Cheers*, our online forums and other peer support services.

We will undertake consultations to provide evidence of the impact of the illness of the lives of people with M.E. to use in our influencing work.

- We have established an up-to-date picture of funding and specialist healthcare provision for people with M.E., publishing our Spotlight on specialist services report in 2016–2017.
- Based on the findings in this report, we will explore how we can work with patients and professionals to develop a framework for collecting data on M.E. prevalence and clinical pathways; and a national blueprint for appropriate, patient-led specialist M.E. services that consistently meet the needs of people with M.E.
- We will undertake a five-year update consultation in 2018–2019 on the impact of the illness on health, welfare, education, employment and training.

We will continue to strengthen our financial position and achieve the levels of income and efficiency we need to deliver the promises we make to people affected by M.E.

- We continue to ensure that our organisation is as efficient and responsive as it can be.
- We will undertake work to refresh our Online M.E. Centre and update our IT infrastructure, including our membership/supporter database, to ensure we can effectively support our members, donors and supporters, and make the most of opportunities to maximise our income.
- We will raise £3 to £5 for every pound we spend on fundraising.



We will not rest until people with M.E. receive support at every level

“A good strategy must fully acknowledge the past even as it looks robustly forward. Action for M.E. is thirty years old, yet for almost all that time we have had to expend scarce resources on counteracting an unfavourable tide of opinion and practice. Although the tide is finally turning, we have a lot of ground to make up. That is why it is essential to allocate 30% of our resources to the ongoing task of educating and informing healthcare professionals, the media and the general public. We cannot rest until M.E. is recognised as a devastating illness.

“Research is also vital, but it must be good research. For too long M.E. research has been characterised by patchy, poor-quality studies, all too often driven by a narrow range of pre-formed theories rather than impartial, gold-standard science. We are committed to driving forward the collaborations and international dialogue needed to build up a critical mass of research into every aspect of the disease. Biological markers, diagnostic tests and targeted treatments are the immediate goals. We will not rest until they are achieved.

“Supporting people with M.E. has always been at the heart of this charity. This strategy confirms that it will continue to be so. No one with this illness should have to endure isolation and despair. We will not rest until children, young people and adults affected by M.E. receive proper support at every level.”



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Clare Francis
President
Action for M.E.

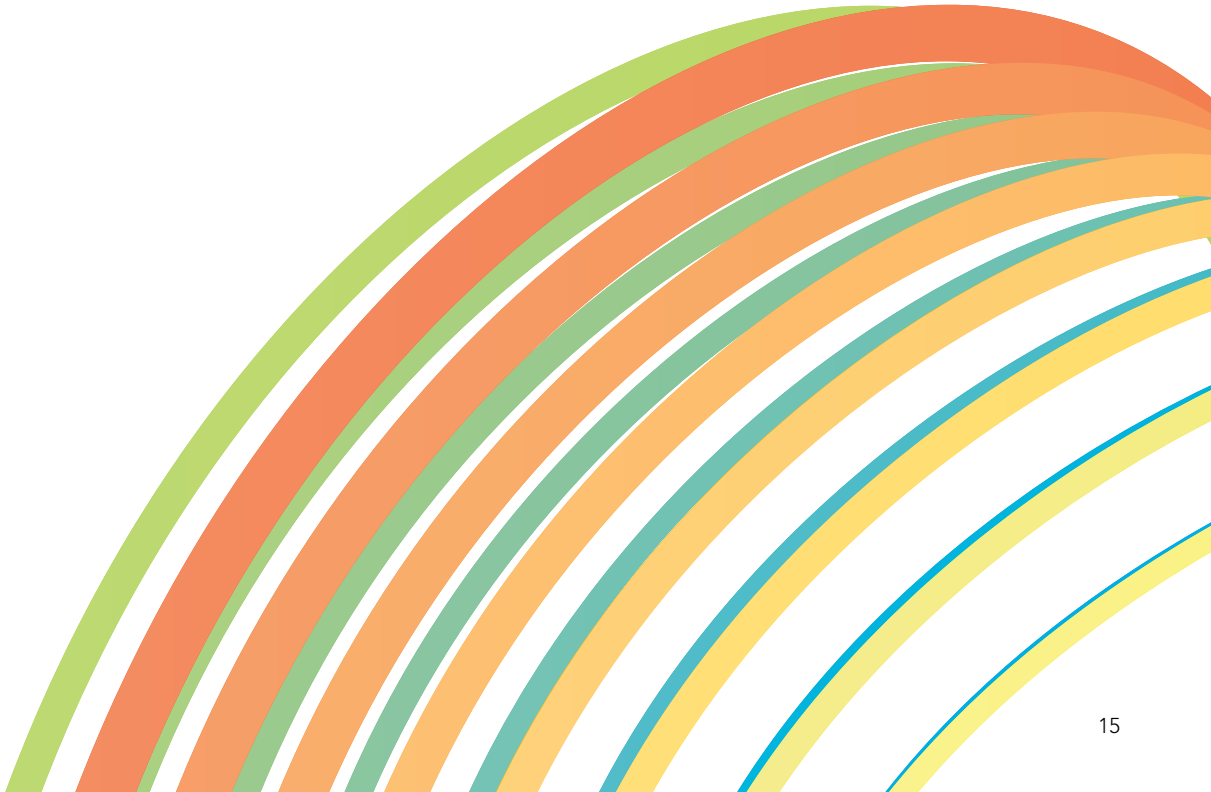
Be part of our movement for change

You can work with us to take action to help end the ignorance, injustice and neglect experienced by people with M.E.

Make a difference by:

- understanding key facts about M.E. and its impact at www.actionforme.org.uk/what-is-me
- sharing what you know to raise the profile of M.E. and its effects
- offering empathy and practical support to children, young people and adults affected by M.E. – find out how at www.actionforme.org.uk/you-can-make-a-difference
- take action on social media to raise knowledge and understanding of M.E. by sharing our resources and films about M.E.
- sharing your skills, expertise and time to support our work – contact us to find out more
- adding your voice to thousands of others affected by M.E. by becoming an Action for M.E. supporting member and joining our movement for change – visit www.actionforme.org.uk/join-us
- raising vital funds to enable us to take action for people with M.E. Call our fundraising team now on 0117 937 6626.

Together we can secure much needed improvements in education, health and social care, welfare policy and research investment.



“Thank you Action for M.E. for fighting our corner – for fundraising to make research happen, for campaigning to get our voice heard, for supporting us lot living with the illness in many ways, and for working to raise awareness/understanding of M.E. I’m grateful for that and for all the people who give their time to work/volunteer for and support the cause. We deserve better. Together we can fight for that.”

Glen Buchanan, Action for M.E. supporter



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